

## SOCIETY UPDATE



The British Lymphology Society (BLS) is a multidisciplinary group of healthcare professionals and others who are directly involved in promoting the management of lymphoedema, or interested in furthering the work of the society. The aims of the society are: to promote awareness about lymphoedema to the public and healthcare professionals; to promote the need for equitable, accessible and sustainable services for all people living with lymphoedema; to actively encourage research into the management of lymphoedema, and other areas related to the condition; and to produce evidence-based standards of care to underpin treatment for the long-term management of lymphoedema. Other areas being developed over the next three years include: working in closer partnership with other organisations, both nationally and internationally; joint conferences with European and international colleagues; raising the profile of lymphoedema at a national level; developing our website and improving communication with both our members and the public; improving the value of the BLS for its members; and setting standards for lymphoedema education to meet the needs of identified patient groups. For more information, please email: [admin@blsac.demon.co.uk](mailto:admin@blsac.demon.co.uk) or telephone: 01959 525524.



The Lymphoedema Association of Australia (LAA) was founded by John and Judy Casley-Smith in 1982 to encourage research into lymphoedema and its treatment, and to spread information among doctors, therapists and patients. The LAA website contains an excellent summary of information about lymphoedema, its causes and treatment, including views on bandaging and garments and related matters, together with essential reference material. The site was last updated in 2003, but will be totally refreshed and updated in 2007 by Neil Piller of the Flinders Medical Centre Lymphoedema Assessment Clinic. The website contains many useful suggestions about treatment. Patients should discuss these with their doctors and obtain their agreement before doing anything suggested. The site emphasises the importance of the realisation that lymphoedema is quite common, that it can and should be treated, and that, while it can be much reduced, helping the patient to feel better through dealing with subjective complaints is vital. Further details about the web page can be accessed at: [www.lymphoedema.org.au](http://www.lymphoedema.org.au) or obtained from Professor Piller at: [neil.piller@flinders.edu.au](mailto:neil.piller@flinders.edu.au) or by going to [www.flinders.sa.gov.au/lymphoedema](http://www.flinders.sa.gov.au/lymphoedema).



The Dutch Lymphoedema Network (NLNet) provides a unique forum in the Netherlands for both patients and healthcare professionals involved in the management of lymphoedema and lipoedema. It started in 2000 and offers information and contact details for therapists and regional support groups, as well as a discussion forum. In 2006, NLNet was joined by other leading organisations in the Netherlands involved in lymphology. It facilitates discussion and the exchange of ideas on the internet; enhances public awareness; stimulates multidisciplinary healthcare cooperation, and encourages an interest among professional stakeholders. To achieve these goals, there is a Health on the Net Foundation-certified internet website ([www.hon.ch](http://www.hon.ch)), a journal (*Lymfologica*), regional patient support groups and an annual congress. Membership costs 20 euros per annum, which entitles you to full access to the internet platform and other offers from NLNet. NLNet puts together national and international guidelines on lymphoedema and is actively cooperating in the development of a European Lymphoedema Network ([www.european-lymphologic-network.de](http://www.european-lymphologic-network.de)) which has links to other international organisations. For further information please visit: [www.lymfoedeem.nl](http://www.lymfoedeem.nl).



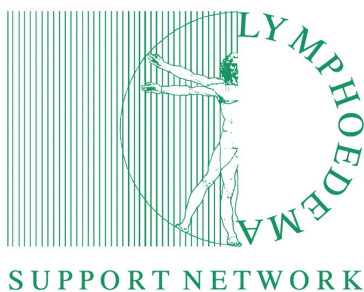
The Society of German-speaking Lymphologists was founded in Vienna in 1986, during the International Society of Lymphology's Congress. The goal of the society is to support basic research in lymphology, as well as to encourage the spread of clinical knowledge among practising doctors. The society holds congresses every two years with varying themes; lymphology in oncology; lymphology in geriatrics; lymphology in endocrinology, etc. The congress organisation encompasses a session for basic lymphology, a session for clinically practising lymphologists, as well as further education and training for practising doctors and lymph therapists. The Society of German-speaking Lymphologists also presents the Mascagni medal for outstanding life's work. This presentation takes place during the congress. The Society of German-speaking Lymphologists works closely with the European Society of Lymphology (ESL), and hopes for intensified cooperation and exchange of experiences with the British Lymphology Society (BLS) and the Lymphoedema Support Network (LSN).



The German Society of Lymphology (*Deutsche Gesellschaft für Lymphologie*, DGL) has existed since 1976 as an approved charitable society. Its purpose is to support research and training in the field of the lymphology and allied subjects, e.g. other oedematous diseases. Cooperation exists with other medical societies, lymph drainage centres, the lymph network, medical supply groups and patient organisations. Its main tasks are: support of research in lymphology (theory and practice); support of education and advanced training in lymphology; and publishing research and clinical results. The journal, *Lymphologie in Forschung und Praxis* (*LymphForsch*), is the official publication of the German Society of Lymphology, the Society of German-speaking Lymphologists and the Society for Manual Lymph Drainage (Dr Vodder) and Related Therapies. *LymphForsch* is published twice a year and contains original articles in German dealing with clinical and scientific studies of the lymphatic system. It includes related fields, editorials, abstracts and information from the three societies. Summaries of the original articles are available in German and English. For more details, please visit our website at: [www.dglymp.de](http://www.dglymp.de) or [www.lymphnetzwerk.de](http://www.lymphnetzwerk.de).



The Lindsay Leg Club® model was originally developed in 1995 when Ellie Lindsay was working as a district nursing sister in rural Suffolk. With the support of the local community, she established the first Leg Club. The emphasis was on providing a clinic in which social interaction, participation, empathy and peer support could ease loneliness for people with leg-related problems. Within a short time, it became evident that many patients were experiencing real benefits in terms of morale and quality of life. There are 16 Leg Clubs in the UK and four in Australia. A further three Leg Clubs are opening in the UK in September, and Ellie will officially open another two in Queensland in October. In the field of leg ulcer and lower limb lymphoedema management, the Lindsay Leg Club® model delivers an environment for truly patient-centred holistic care through a synergistic combination of four binding principles: a non-medical setting; collective treatment; open accessibility; and an integrated 'well leg' regime. Today's healthcare world makes it too easy to lose sight of the importance of the caring ethos and the quality of patients' lives. The Leg Club model of care, however, has shown that these two seemingly incompatible aims can be united. For more details, visit its website at: [www.legclub.org](http://www.legclub.org).



The Lymphoedema Support Network (LSN) takes the lead role in educating and supporting people with lymphoedema by providing a high standard of information and promoting self-management. Since its inception in 1991, the LSN has evolved into an independent and influential charity. It is the only national patient-led organisation offering information and support to people with this condition. The charity is the largest information resource for lymphoedema in the UK, producing an ongoing series of factsheets. Initially they were for patients, however, the high standard of this information has led to healthcare professionals ordering them for use in hospitals, hospices and lymphoedema clinics. LSN factsheets are considered to be 'gold standard', written by healthcare professionals, with additional input from LSN trustees and members. Two self-help videos/DVDs produced for patients have also proved to be a valuable resource and teaching aid for healthcare professionals. The charity also operates an information and support telephone line, produces a quarterly newsletter, maintains an up-to-date website and promotes the formation of local support groups throughout the UK. The LSN is committed to raising awareness of lymphoedema and campaigns at national level for improved service provision for all lymphoedema patients. For more information, visit: [www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn).



President: Prof.C.Moffatt

The Leg Ulcer Forum (LUF) exists to advance education and offer support to healthcare practitioners involved in the management of patients with leg ulcers and related conditions. The executive comprises specialist practitioners and educationalists who share a common bond in wishing to advance the care of patients through dissemination of new research and evidence-based practice. The forum is proactive on behalf of its members and is currently involved in responses to Department of Health initiatives, debates on development of skills and competencies in an increasingly diverse workforce, as well as educational projects. Current LUF educational projects include producing patient leaflets and events to disseminate evidence-based practice. Members of the executive have been involved in national guidelines, audit and a considerable body of literature related to leg ulcer issues. Membership of the Leg Ulcer Forum is open to any healthcare practitioner involved in the care of patients with leg ulcers and related conditions. The £15 annual membership fee gives you a subscription to the annual LUF journal, a discount at LUF educational events and copies of all the *NTWound Care* supplements. You will have access to the resources on the website, copies of all the educational material we produce and much more. To find out more about our work, visit [www.legulcerforum.org](http://www.legulcerforum.org) or email: [legulcer.forum@btopenworld.com](mailto:legulcer.forum@btopenworld.com), or telephone: 01480 494842.



Svenska Ödem Förbundet (SOF) (The Swedish Society for Oedema) is a community of interests for patients with lymphoedema. SÖF spreads information and knowledge about lymphoedema and its treatment, for patients and healthcare professionals, throughout Sweden. Due to the shortage of lymph-therapists and the scarcity of knowledge within the medical service, it is not always possible to receive good treatment. The Society hopes to improve the treatment of lymphoedema and to achieve a uniformity across the country by influencing politicians and decision-makers in the medical service so that all the lymphoedema patients in Sweden obtain adequate treatment. The society promotes the education of more lymph-therapists, to a level which obtains the same qualification as that from an institute of advanced studies. The society plans to establish 10 new local societies in the next year. Members of SÖF have increased by 20% during the past few years, with many members wanting to establish local societies to enhance the exchange of knowledge and experience within a smaller network. Further details about SÖF can be accessed at: [www.lymfan.nu](http://www.lymfan.nu) or email: [info@lymfan.nu](mailto:info@lymfan.nu).



The National Lymphedema Network, Inc (NLN) is an internationally recognised, non-profit organisation founded in 1988 to provide education and guidance to lymphoedema patients, healthcare professionals and the general public by disseminating information on the prevention and management of primary and secondary lymphoedema. The NLN is supported by tax-deductible donations and is a driving force behind the movement in the US to standardise quality treatment for lymphoedema patients nationwide. In addition, the NLN supports research into the causes and possible alternative treatments for this often incapacitating, long-neglected condition. The NLN provides: a toll-free recorded information line (1-800-541-3259); referrals to lymphoedema treatment centres, healthcare professionals, training programmes and support groups; a quarterly newsletter (*LymphLink*), with cutting edge articles and information about medical and scientific developments, support groups, pen-pals/net-pals, advocacy/legislative issues and listings of lymphoedema meetings around the world; educational materials for healthcare professionals and patients; a biennial international conference for healthcare professionals (next conference: November 2006); a biennial patient summit for patients, those at-risk, family members and advocates; an extensive computer database with patient medical data and more. For more information, go online to: [www.lymphnet.org](http://www.lymphnet.org) or email [nlm@lymphnet.org](mailto:nlm@lymphnet.org).

To include news and events about your society in **SOCIETY UPDATES**

Please send details (in no more than 200 words) plus a jpeg of your logo, to [binkie.mais@wounds-uk.com](mailto:binkie.mais@wounds-uk.com)

We want to keep our readers abreast of all society activities concerning the advancement of the management and treatment of lymphoedema. These pages are intended to help you to share your news with others throughout the world who are also working to improve the standards of care for those with lymphoedema and related conditions, so please contribute.

The closing date for the next issue of *Journal of Lymphoedema* is Friday 23 February 2007